



Queensland  
**Aphasia**  
Research  
Centre

# Researching the Personal: The Contribution of Lived Experience in Liminal Research Spaces

**QUT**

FACULTY  
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Australian Centre for  
Health Law Research



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# Acknowledgment of Country

The University of Queensland (UQ) acknowledges the Traditional Owners and their custodianship of the lands on which we meet.

We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We recognise their valuable contributions to Australian and global society.





## A NOTE ON TERMS

- Defining Severe/profound intellectual disability
- PIMD = Profound Intellectual and Multiple Disabilities
- Grounded in –
  - Understanding
  - Communication
- Assistance with all tasks of everyday life
- Requiring assistance with all administrative and legal decisions

# RESEARCH, INCLUSION, AND PROFOUND INTELLECTUAL DISABILITIES

- Inclusion and **the Topic**:
  - ‘Insider’ researcher position
  - ‘Choosing’ to do research in this area
- Inclusion and **Participation in Research**
  - Ethical clearance
  - Whose lived experience?
- About the **Researcher**:
  - Interviews as *conversation*.
  - Shared: Practicalities; Experiences; Humour; Emotion
- **Presence**

# RESEARCHING THE PERSONAL

“Even if philosophy whitewashes disability and therefore passes over children such as ours, with their impairments, with the special care they require, their lives direct us to the point and purpose of philosophy—the pursuit of wisdom. Their lives help us in our quest to discern what the meaning of life is; what makes life worth living or what makes a life a good life; what makes relationships ethical; what personhood is; how to understand beauty, anomaly, function, capacity, joy; what justice and equality are. I have always, to some extent or other, seen philosophy as refracted through my experience with Sesha. It has taken me a long time to write about it.”

*Eva Feder Kittay, 'Love's Labor Revisited' (2002) 17(3) Hypatia 237-250, 239 ~*



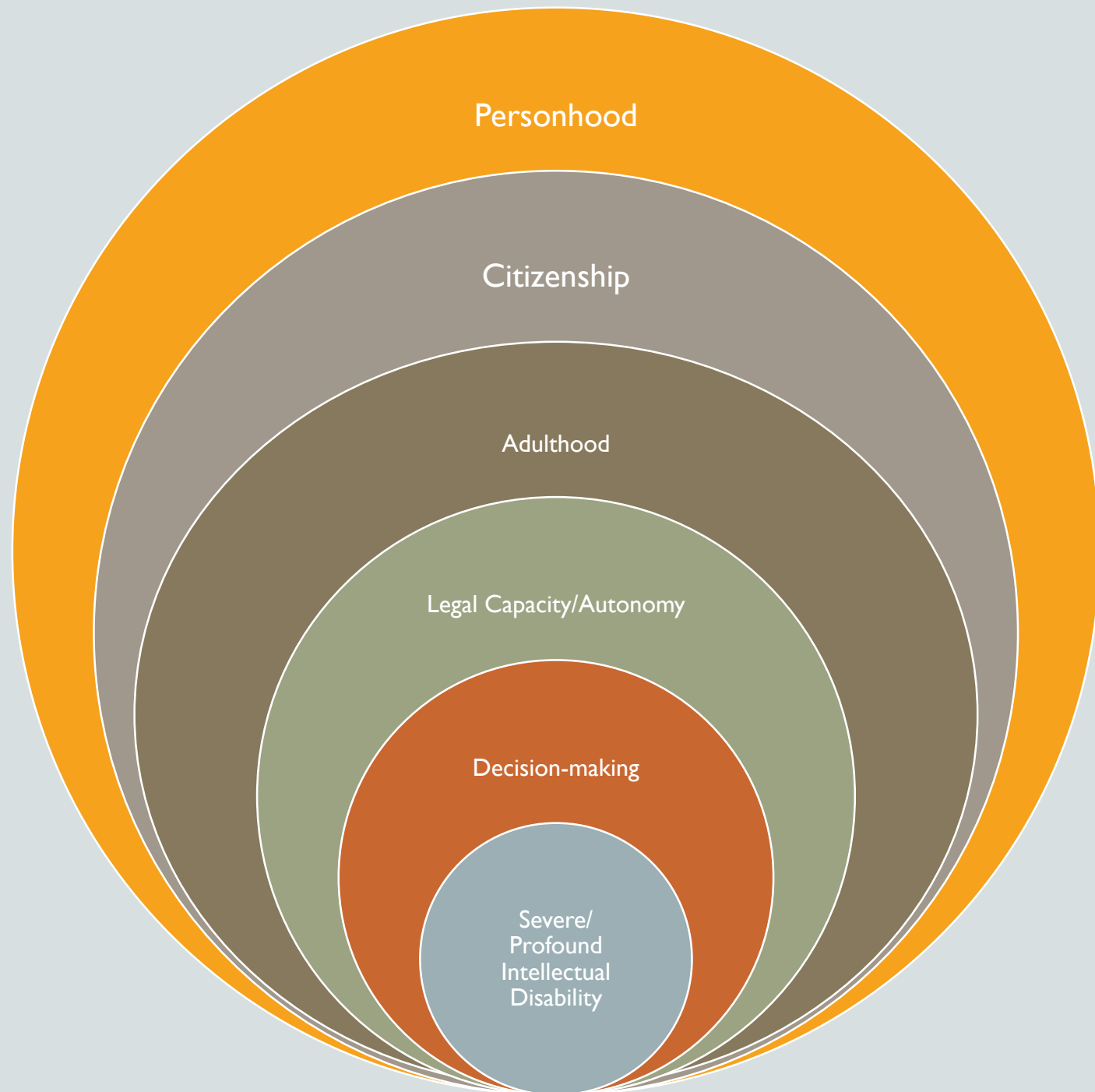
## THE RESEARCH: OVERVIEW

The Transition to Adulthood of  
People with Severe and Profound  
Intellectual Disabilities in Australia:  
A Socio-Legal Examination (2023)

Supervisors: Associate Professor Shih-Ning

Then & Dr Elizabeth Dickson

*Queensland University of Technology*



# INCLUSION AS PARTICIPANTS?

## Ethics and Regulation

- Ethical Clearance (!!)
- Consent/Assent
- Substituted Consent
- Parent + Person with PIMD Dyads

## Participation

- 20 Interviews: 2 excluded
- 17 mothers and 1 father
- 7 young women; 11 young men
- **12 pairs, 6 parent only**
  - 2 = scheduling
  - 2 = parent decision/didn't realise
  - 2 = person's disability(?)

## Inclusion?

- Realities of participation
- Importance of presence
- Perceptions of parents
- Insider researcher

# Insider Research: Interviews as Conversation



## Practicalities

**Hetty:** Oh, and I got that three hours paid care, that's all I ever had, free. Did you get that, that Home and Community Support thing?

**Michelle:** Yes, yes, it was 3 or 4 hours a week? \$20 an hour or something?

**Hetty:** Yes, that one! We got that when he was a school, too. But I just couldn't believe that, you know, before that I got nothing. And that \$22,000 didn't go very far at all, did it.

*Interview 8: Hetty, mother of Jack (age 19)*



**Michelle:** Was that for one-on-one support?

**Jennifer:** [laughs] Oh, no, no. It was one-on-two one day a week, and one-on-three the other days a week.

**Michelle:** Because the DSQ funding wouldn't cover lower ratios.

**Jennifer:** Oh no, by the time we transitioned from DSQ to NDIS, I think he was getting \$25,000 a year?

**Michelle:** The maximum.

**Jennifer:** Yeah, yeah. And we had to pay for the transport ourselves. [...] The actual program was 9 until 2.30.

**Michelle:** People often don't realise that a "day" program will only go until 2pm.

**Jennifer:** Yes! It's certainly not 9 til 5! It's very difficult. I mean, you can pay extra to have them supported longer, but that's one on one usually, and under the DSQ system, no one could afford that with their funding, could they?

*Interview 12: Jennifer, mother of Tom (age 23)*



## Experiences (+ Humour)

**Alison:** At one point, they gave Mary a pen, they said, “she can sign the application!” Mary doesn’t know what a pen is! Anyway, later she threw it and it nearly hit the planner in the eye. [laughs] I bet you had similar?

**Michelle:** Oh, yes, they rang to ask about Daelle’s plan once and asked me to put Daelle on the phone!

[both laugh]

**Alison:** Yes, I wish! I wish I could put her on the phone! Mary can’t hear, she can't speak, **she can't make any decisions on behalf of herself, and she doesn't fit into their system.**

*Interview 1: Alison, mother of Mary (age 18).*



## Emotions

**Anne:** There's just not many places for complex needs after school are there?

**Michelle:** We miss school.

**Anne:** Oh, yes, it's a big hole for everybody. Lots of our people would use something like school as adults, wouldn't they?

*Interview 10: Anne, mother of Billy (age 18).*



**Katherine:** When were at early intervention, you know, I was on the fundraising committee, I used to do this, used to that. You know, I was on all the committees and did all the stuff. I had a lot of energy [laughs] And then... there's a Facebook group for the gene [causing Molly's PIMD] - it's a Facebook community - and you see all these Mums with young ones on there, and they're so proactive. **But I'm 58 now, and I'm tired. I did all that 20 years ago.** I can remember somebody saying to me: when you accept what's going on, you run out of puff.

**Michelle:** For me, when she got older... **there's an acceptance of how things are,** that all of this isn't going to change.

**Katherine:** That's what I think. You know, when they're little, you want to do as much as you possibly can to give them the best outcome. But then you go: well, I did that, and maybe that made a difference, but mostly it didn't, and now what? She is getting worse not better, and **she's all grown up now. So, now what?**

**Michelle:** And even if she never does all that stuff, **maybe that's okay.**

**Katherine:** Yes! I thought: **if I appreciate what she can do, instead of focusing all the time on what she can't do.** So, I think when I accept that, I stop worrying so much about what's going to happen to her.

**Michelle:** Yes, yes! It's funny, because we've both referred to ourselves as 'slack' since they left school, but I'm just more happy to accept how she is, you know? And I'm more confident about what I want to work on with her to preserve.

**Katherine:** I suppose our expectations have gone. We're not expecting new things. I mean, **what are we putting them though, you know? And who is that for?**

*Interview 19: Katherine, mother of Molly (age 21).*



# Presence?

- **Recognition** of what the research is about
- Allows realities of experience and difference to be **present**
- Includes the person within their **capabilities**
- Changes the nature and **focus** of the conversations
- Grounds **conversations**
- Privacy and consent?
- Dignity and respect?
- Is this **inclusion**?
- Importance of **visibility** and **presence** in research spaces
- Should we do more research like this?

If you have experience supporting someone who receives aged care services in Australia and want to do an interview with me about all things aged care, fill in the EOI at the link!



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